



NCBDDD 10 YEARS OF SERVICE

PROJECT WORK PLAN

Project Overview, Goals, and Theme

Overview

Since its establishment in 2000, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) and its partners have advanced public health practice in the fields of birth defects, disabilities, and blood disorders. NCBDDD works to advance the health and well being of our nation's most vulnerable populations.

To honor a decade of progress and showcase the exceptional work of our collective organizations, NCBDDD and its partners are carrying out a series of events and activities throughout 2011. NCBDDD is also utilizing this milestone as an opportunity to focus on the strategic direction of the Center.

Goals

The goals of *10 Years of Service* include the following:

- Promoting the tremendous progress NCBDDD and its partners have made in the past 10 years.
- Recognizing NCBDDD as a leader in the fields of birth defects, disabilities, developmental disabilities and blood disorders.
- Increasing awareness of NCBDDD's current programs and priorities.
- Expanding NCBDDD's partnership base and strengthening engagement of existing partners and stakeholders.
- Inspiring and unifying staff around the Center's mission and strategic priorities.
- Garnering support for the needs of critical NCBDDD programs and activities.

Theme

The theme is, “***Power to Inspire Generations.***” This theme is about honoring the pioneering spirit of the Center, partners, and communities and empowering today’s generation to keep this spirit alive for generations to come. Many of our advancements and innovations in public health are due to the contributions of legends in the field that have paved the way to more promising health outcomes.

Alignment with Center Goals and Priorities

The 10th Anniversary contributes to the following Center goals and priorities:

Goals

- Prevent birth defects and developmental disabilities.
- Improve health outcomes among children through screening, early diagnosis, and intervention.
- Eliminate health disparities associated with disability.
- Prevent death and disability associated with blood disorders.

The Center’s three over-arching priorities

- Prevent major birth defects attributable to maternal risk factors.
- Prevent death and disability due to deep vein thrombosis (DVT) and pulmonary embolism (PE).
- Reduce disparities in obesity and other health indicators in children, youth and adults with disabilities.

Governance

10 Years of Service Senior Leadership Committee

The Senior Leadership Committee assists in strategic planning for the *10 Years of Service* project and serves as NCBDDD’s champions.

The Senior Leadership Committee consists of the Executive Leadership Team. The Senior Leadership meets weekly (Tuesdays at 1:00 pm).

10 Years of Service Core Team Members

The Anniversary Team is responsible for day-to-day management of the planning, execution, ongoing communication, and all other aspects of the project. The Core Team has ad hoc bi-weekly meetings.

Core Team members

Senior Advisor: Alison Johnson
Project Oversight: Kate Galatas
Project Management: Amanda Tarkington
Project Support: Esther Wilson

Internal Anniversary Workgroup

The Internal Workgroup is responsible for the planning and implementation of all events and activities. Members of the Internal Workgroup participate in regular meetings, contribute to key decisions, and serve as liaisons with staff in the divisions. The committee includes a cross-section of NCBDDD personnel in order to ensure a range of involvement and expertise from the Center. The Internal Anniversary Workgroup meets bi-weekly (Tuesdays at 1:30 pm).

The Internal Committee's tasks include:

- Developing and finalizing the project work plan.
- Contributing ideas, guidance, and feedback related to the planned events.
- Helping to identify key partners, champions, celebrities, dignitaries, and spokespersons for events and securing their participation.
- Promoting and communicating about activities to their division and CDC colleagues.
- Providing support and guidance to the External Partner Committee.

Internal Committee Members

Amanda Tarkington	Kate Galatas
Alison Johnson	Kara Duwe
Angie Colson	Kenneth Surdin
Cara Mai	Kim Raymond
Carol Cook	Kimberly Smith
Cindy Sayers	Kinzi Lee
Dionne Mason	Kristy Marquez
Dorthina Grant	Martha Alexander
Esther Sumartojo	Mary Helen Witten
Esther Wilson	Melody Stevens
James Kucik	Mike Soucie
Joy Hugick	Monica Mann
Merita Craddock	Natasha Singh
Julia Richardson	Sally McAlister
Julie Hentz	

Sub-Committees

Detailed planning and execution primarily occurs through sub-committees. The sub-committee chairs are as follows:

Event	Point of Contact	E-mail Address
Events	Julia Richardson	Gun2@cdc.gov
	Katie Kilder Green	kpk9@cdc.gov
Communications & Marketing	Julie Hentz	Atg4@cdc.gov
Policy & Planning	Kim Raymond	jpq5@cdc.gov
Partner Planning	Melody Stevens	sme1@cdc.gov
	Tamara Maze	Chi2@cdc.gov
Science	Esther Sumartojo	ESumartojo@cdc.gov

External Partner Committees

The External Partner Committees consists of NCBDDD partners that help guide and direct the planning of the 10th anniversary. The External Partner Committee meets monthly (usually the 3rd Monday of each month).

For a complete list of external partners see Appendix A.

Core Partners Committee

Some of the responsibilities of the Core Partners planning committee include:

- Assisting in securing key resources for the events. This includes in-kind donations, spokespersons, and venues.
- Helping to identify champions and events that align with NCBDDD's priorities and goals.
- Increasing awareness of the events with their constituents through communication and marketing activities.
- Providing guidance and recommendations on the overall planning of events and serving as a sounding board for the internal planning committee.
- Communicating with our legislative partners about the planned events.

The Core Partners Committee consists of the following:

Organization	Member	E-mail Address
CDC/OD/OCS	Charlie Stokes	CStokes@cdc.gov
AAP	Holly Griffin	HGriffin@aap.org
American Association on Health	Roberta Carlin	rcarlin@aahd.us

and Disability (AAHD)		
March of Dimes	Emil Wigode Melissa Habedank	EWigode@marchofdimes.com MHabedank@marchofdimes.com
Association of University Centers on Disabilities (AUCD)	George Jesien	gjesien@aucd.org
Christopher & Dana Reeve Foundation	Joseph Canose	jcanose@christopherreeve.org
City MatCH	Kathleen Brandert	kbrandert@unmc.edu
American Association of People with Disabilities		
MorSolutions	Gaylon Morris	gaylondmorris@gmail.com
MorSolutions	Julie Beckett	waivermom@earthlink.net
Association of University Centers on Disabilities (AUCD)	Adriane Griffen	agriffen@aucd.org
United Cerebral Palsy	Chris Thomson	cthompson@ucp.org
Special Olympics International	Karl Hejlik	khejlik@specialolympics.org
American Society of Hematology (ASH)	Stephanie Kart Kaplan	skaplan@hematology.org
National Association of County and City Health Officials (NAACHO)	Laura S. Snebold	lsnebold@naccho.org
Friends of NCBDDD	Clarke Ross	Clarkeross10@comcast.net
Association of Maternal and Child Health Programs (AMCHP)	Mike Fraser	mfraser@amchp.org

Ad Hoc Partners Committee

In addition to the responsibilities above, an ad hoc committee of partners assists with field hearings and other sub-committee work, as needed. The Ad Hoc Partners Committee consists of the following:

Organization	Member	E-mail Address
American College of Obstetricians & Gynecologists	Debra Hawks	dhawks@acog.org
American College of Obstetricians & Gynecologists	Jeanne Mahoney	jmahoney@acog.org
Autism Society of America	Marguerite Kirst Colston	
Autism Speaks		
Family Voices, Inc.	Sophie Arao-Nguyen, Ph.D	san@familyvoices.org
Special Olympics	Dr. Stephen Corbin	scorbin@specialolympics.org
Easter Seals	Mary Andrus	mandrus@easterseals.com
Spina Bifida Association	Cindy Brownstein	cbrownstein@sbaa.org
Spina Bifida Association	Sara Struwe	sstruwe@sbaa.org
National Healthy Mothers, Healthy	Melissa Dilber	MDilber@hmhb.org

Babies Coalition		
National Blood Clot Alliance	Alan Brownstein	abrownstein@stoptheclot.org
Sickle Cell Disease Association of America	Sonja Banks	sbanks@sicklecelldisease.org
Trust for America's Health		
Association of State and Territorial Health Officials (ASTHO)	Ellen Pliska	epliska@astho.org
Association of State and Territorial Health Officials (ASTHO)	Albert Terrillion	aterrillion@astho.org
National Association of County and City Health Officials (NAACHO)	Cindy Phillips	cphillips@naccho.org
Amputee Coalition of America	Kendra Calhoun	kcalhoun@amputee-coalition.org
The Arc of the United States and United Cerebral Palsy	Peter Berns	berns@thearc.org
The Arc of the United States and United Cerebral Palsy	Liz Savage	savage@thedpc.org
Genetic Alliance	Molly Brenner	mbrenner@geneticalliance.org

Implementation

The implementation of this project is divided into the following categories:

Phase I: Planning and Governance

From May 2010 to July 2010, the project planning and governance involved the creation of a project work plan and timeline; establishing a governance structure, including an internal workgroup and external partner committees; creating branding for the project; and writing key messages and “stories.”

Committee meetings are as follows:

Group	Frequency	Time
Senior Leadership Committee	Weekly	Tuesdays at 1:00 pm
Core Team	Ad hoc (bi-weekly)	TBD
Internal Anniversary Workgroup	Bi-weekly	Tuesdays at 1:30 pm
Subcommittees	TBD	TBD
External Partner Committee	Monthly	3rd Monday of each month

Phase II: Events and Activities

The Center is framing *10 Years of Service* events around three key audiences: partners, legislators, and employees. Our calendar of events and activities (see below) focuses on the engagement our target audiences around key center priorities and events.

Community Engagement Events

Event Center Priority	Location	Timeframe	Internal POC	Partner Engaged
Congressional Hill Opening <i>- Early Childhood Development</i>	Washington, DC	March 3,2011	Kim Raymond	March of Dimes
Community Engagement <i>- Autism Spectrum Disorder: Understanding An Urgent Public Health Concern</i>	New Jersey	April 29, 2011	Melody Stevens	ASA, Autism Speaks
Community Engagement <i>- Sickle Cell Awareness</i>	Atlanta, GA	June 23,2011	Carol Cook	
Community Engagement <i>- Congenital Heart Defects</i>	Chicago, IL	August 2011	Jim Kucik	
Community Engagement <i>- NCBDDD Connects with the Community</i>	Denver, CO	August/ September 2011	Steve Richardson	
Closing Event <i>- Disability and Obesity</i>	Washington, DC	November 2011	Kim Raymond	

Partners

NCBDDD recognizes the importance of partners' engagement in the planning and implementation of *10 Years of Service* activities. Our goals for engaging partners are to expand NCBDDD's partnership base; strengthen engagement of existing partners and stakeholders; promote awareness of Center-wide priorities and programs; and increase the impact of the science. We are conducting the following partner events and activities:

- Launching a series of communication activities for partners only (e.g. NCBDDD partner updates, partner page for the 10th anniversary, etc).
- Organizing events at existing partner conferences. Each event will focus on a different Center priority.

- Concluding our anniversary year with an event that includes an awards ceremony to honor partners for their 10 years of accomplishments.

Employees

NCBDDD employees have greatly contributed to the overall success and sustainability of NCBDDD programs and activities over the past decade. *10 Years of Service* is very much about showing appreciation for our employees and acknowledging their ongoing contributions to the Center. Our goals during 2011 are to inspire and unify NCBDDD and CDC staff around the Center's mission and strategic priorities. We are hosting the following employee events and activities:

- An employee kickoff event to launch 10 Years of Service (February 2011).
- A celebration to highlight employee contributions (e.g. honors and awards).
- Volunteering throughout the year as a Center in various awareness walks (e.g. Autism Walk).
- Profiles of employee contributions highlighted on the Intranet.

Phase III: Promotion and Marketing

The Center seeks to introduce and reinforce key messages to target audiences through the strategic implementation of the *10 Years of Service* promotions and marketing plan. Our promotions and marketing goals are to highlight the impact and progression of our key programs and bring attention to *10 Years of Service*. Examples of the promotion and marketing activities include:

- Incorporating *10 Years of Service* key messages in all communications and media materials in 2011.
- Developing and implementing a series of social media tools that CDC and its partners can use to help promote *10 Years of Service* to their constituents.
- Partnering with a non-traditional and a public health partner to promote NCBDDD's programs and priorities through the media.
- Creating a video about *10 Years of Service* based on the theme.
- Developing a *10 Years of Service* Website.

Ongoing Communication

Updates to key internal and external stakeholders will help ensure that people have an opportunity to learn about progress, challenges, and next steps. It will also provide a way for people to regularly express concerns or provide other constructive feedback. Ongoing communication will include the following activities:

- Bi-weekly internal workgroup meetings.
- Monthly external partner committee meetings.
- Monthly progress reports to the executive committee, senior staff, workgroups, and committees.
- Quarterly updates to all NCBDDD staff.
- CDC Connects Articles.

Media Communications

The *10 Years of Service* Media Plan is designed to increase public awareness about NCBDDD's strategic priorities. We are strategically managing our relationships with media outlets and our target audiences by developing timely, accurate, and concise *10 Years of Service* messaging and media communications.

Our Media goals are to promote awareness of NCBDDD's strategic priorities, "center level, and division level priorities" and programs; and increase recognition of NCBDDD and our partners as leaders in the fields of disabilities, blood disorders, birth defects and developmental disabilities. We are highlighting NCBDDD and our partner's past successes in the area of prevention, research and education.

Web Communications

The *10 Years of Service* Web Plan is designed to provide information about our 10th Anniversary events and to increase awareness around our primary focus areas. We have designed our Web Plan to incorporate internal, Intranet, communications and external, Internet communications.

Internet

The *10 Years of Service* Intranet Web page is designed to highlight our *10 Years of Service* celebratory activities and strengthen communication with existing partners about *10 Years of Service* strategic priorities. The goals of the Web page are to recognize NCBDDD and our partner's past successes in the area of prevention, research and education in each of the Center's focus areas and to strengthen communication with existing partners about NCBDDD's strategic priorities. The *10 Years of Service* Web page has the most current calendar of events, partners information, and a robust science features section that highlights a decade's worth of articles written by members of our Center. The *10 Years of Service* Website is <http://www.cdc.gov/ncbddd/tenyears/>.

APPENDIX A: INVITED PARTNERS FOR THE PARTNER PLANNING COMMITTEE

10th Anniversary Partners Planning Committee List

American Academy of Pediatrics (AAP)

141 Northwest Point Blvd
Elk Grove Village, IL 60007

Invited Member: Eileen Ouellette, Past President

eouellette@aap.org

Active Member: Holly Griffin Del Monte, Director, Washington Office

mdelmonte@aap.org

202-347-8600

American Association on Health and Disability (AAHD)

110 N. Washington Street
Suite 328J
Rockville, MD 20850

Invited & Active Member: Roberta Carlin, Executive Director

rcarlin@aahd.us

301-963-2343

American Association of People with Disabilities (AAPD)

1629 K Street NW
Suite 950
Washington, DC 20006

Active Member: Andrew J. Imparato- President and CEO

AImparato@aapd.com

202-521-4301

American Society of Hematology

2021 L Street, NW
Suite 900
Washington, DC 20036

Invited Member: Mila Becker, Director of Government Relations & Practice

mbecker@hematology.org

202-776-0544

Active Member: Stephanie Kart, Government Relations Manager

skart@hematology.org

202-776-0544

Association of Maternal and Child Health Programs

2030 M Street NW
Suite 350
Washington, DC 20036

Invited & Active Member: Michael Fraser, PhD, CAE
Chief Executive Officer
mfraser@amchp.org
202-775-0436

Active Member: Lauren Raskin Ramos, Director of Programs
lramos@amchp.org
202-775-0436

Association of University Centers on Disabilities

1010 Wayne Avenue
Suite 920
Silver Springs, MD 20910

Invited & Active Member: George Jesien, Executive Director
gjesien@aucd.org
301-588-8252

Representative Member: Adriane Griffen, Project Director
agriffen@aucd.org
301-588-8252

CDC Foundation

55 Park Place NE, Suite 400
Atlanta, Georgia 30303

Invited & Active Member: Charles Stokes, President and CEO

Christopher & Dana Reeve Foundation

636 Morris Turnpike
Suite 3A
Short Hills, NJ 7826

Invited & Active Member: Joseph Canose, Vice President, Quality of Life
jcanose@christopherreeve.org
800-539-7309 x7206

CityMatCH at the University of Nebraska Medical Center Department of Pediatrics

982170 Nebraska Medical Center
Omaha, NE 68198-2170

Invited Member: Patrick Simpson, Executive Director
psimpso1@unmc.edu

Active Member: Kathleen Brandert, Education and Training Manager

kbrandert@unmc.edu
402-561-7500

Friends of NCBDDD

Invited & Active Member: Clarke Ross, Chair
clarke_ross@chadd.org
301-306-7070

March of Dimes

1275 Mamaroneck Avenue
White Plains, NY 10605
914-997-4488

Invited Member: Marina Weiss, Senior Vice President for Public Policy and Government Affairs
mweiss@marchofdimes.com
Active Member: Emil Wigode
EWigode@marchofdimes.com
Active Member: Melissa Habedank
MHabedank@marchofdimes.com

Special Olympics International

1133 19th Street, N.W.
Washington, DC 20036-3604

Invited Member: Tim Shriver, Chairman, Board of Directors, and CEO (Dr. Trevathan to call; fundraising)
Invited Member: Dr. Stephen Corbin, Senior Vice President, Community Impact
scorbin@specialolympics.org
Active Member: Darcie Mersereau, Vice President for Health Programs
dmersereau@specialolympics.org
202-715-3600

United Cerebral Palsy

1660 L Street, NW
Suite 700
Washington, DC 20036
Phone: 800-872-5827/202-776-0406

Invited & Active Member: Stephen Bennett, President and CEO
stephen@ucp.org

For Field Hearings and Other Activities Like Subcommittee Work:

Association of State and Territorial Health Officials (ASTHO)

2231 Crystal Drive
Suite 450
Arlington, VA 22202

- **Invited Member:** Ellen Pliska, MCH Senior Analyst
epliska@astho.org
571-527-3187
- **Invited Member:** Albert Terrillion, Family and Community Health Senior Director
aterrillion@astho.org
571-522-2314

American College of Obstetricians & Gynecologists

409 12th St, SW
Washington, DC 20024

- Debra Hawks, Senior Director
dhawks@acog.org
202-863-2445
- Jeanne Mahoney, Director, Provider's Partnership
jmahoney@acog.org
202-314-2352

Amputee Coalition of America

900 East Hill Avenue
Suite 205
Knoxville, Tennessee 37915-2566

ACA Advocacy Office
PO Box 73725
Washington, DC 20056

- Phone: 202-742-1885
Fax: 866-599-8994
- Kendra Calhoun, President and CEO
kcalhoun@amputee-coalition.org

Autism Society of America

Autism Society
4340 East-West Hwy
Suite 350
Bethesda, Maryland 20814

- Marguerite Kirst Colston
Vice President, Constituent Relations

Autism Speaks

Family Voices, Inc.

2340 Alamo SE

Suite 102

Albuquerque, NM 87106

- Sophie Arao-Nguyen, Ph.D., Executive Director
san@familyvoices.org
505-872-4775

Easter Seals

233 South Wacker Drive

Suite 2400

Chicago, IL 60606

- Mary Andrus, Assistant Vice President for Government Relations
mandrus@easterseals.com
202-347-3066

Genetic Alliance

4301 Connecticut Avenue, NW

Suite 404

Washington, DC 20008

- Phone: 202-966-5557 x201
Fax: 202-966-8553
- Molly Brenner | Executive Assistant to the President & CEO
mbrenner@geneticalliance.org

JFK Partners

University of Colorado Denver School of Medicine

C234

13121 E. 17th Ave., Room 5116

Aurora, CO 80045

- Cordelia Robinson Rosenberg, PhD, RN
Professor Pediatrics, Psychiatry and Preventive Medicine
Director, JFK Partners
Office Phone: 303-724-7680
Fax: 303-724-7664
Mobile Phone: 303-229-0123
www.jfkpartners.org
E-mail: cordelia.rosenberg@ucdenver.edu

National Association of County and City Health Officials (NAACHO)

1100 17th St NW

2nd Floor

Washington, DC 20036

- **Invited Member:** Cindy Phillips, Senior Advisor
cphillips@naccho.org
202-507-4252
- Robert (Bobby) Pestronk, Executive Director

National Blood Clot Alliance

- Alan Brownstein, Executive Director
abrownstein@stoptheclot.org
914-220-5040

National Healthy Mothers, Healthy Babies Coalition

2000 N. Beauregard St.
6th Floor
Alexandria, VA 22311

- Melissa Dilber, Program Associate
MDilber@hmhb.org

Sickle Cell Disease Association of America

- Sonja Banks, President and COO
sbanks@sicklecelldisease.org
703-837-4792

Special Olympics

1133 19th Street, N.W.
Washington, DC 20036-3604

- Tim Shriver, Chairma, Board of Directors, and CEO (Dr. Trevathan to call; fundraising)
- Dr. Stephen Corbin, Senior Vice President, Community Impact
scorbin@specialolympics.org

Spina Bifida Association

4590 MacArthur Blvd.,NW
Washington, DC 20007-4226

- Cindy Brownstein, President and CEO
cbrownstein@sbaa.org
202-944-3285
- Sara Struwe, Chief Operating Officer
sstruwe@sbaa.org
202-944-3285 x12
- Sherry Arvin, Information and Referral Coordinator
sarvin@sbaa.org
800-621-3141

The Arc of the United States and United Cerebral Palsy

1660 L St., NW

Suite 701

Washington, DC 20036

- Peter Berns, CEO
berns@thearc.org
- Liz Savage, Director of Health and Housing Policy
savage@thedpc.org
202-783-2229 ext. 12

Trust for America's Health

- Contact person: TBD